Research Article

The Importance of Hope for Quality of Life in patients with Multiple Sclerosis

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Abstract

Aims: This study intent to describe the importance of Hope for Quality of Life in patients with Multiple Sclerosis. Evidence has indicated that Hope is important as a buffer between risk factors, physical and psychological health status and quality of life for patients with multiple sclerosis.

Methods: The study was exploratory and descriptive. Setting: A general Hospital in Lisbon Portugal. Participants: 280 patients with Multiple Sclerosis. We explore the relationship between Hope and Quality of Life. The instruments used are Multiple Sclerosis Quality of Life scale (MSQol-54) and the Hope Scale.

Results: The correlation between Hope scale and the domains of MSQOL-54: Physical Health ($r=0.24$, $p<0.05$), Physical Role Limitations ($r=0.25$, $p<0.05$), Emotional Role Limitations ($r=0.35$, $p<0.05$), Pain ($r=0.28$, $p<0.05$),Well-being ($r=0.48$, $p<0.01$), Energy ($r=0.42$, $p<0.01$), Health in General ($r=0.41$, $p<0.01$), Social Function ($r=0.45$, $p<0.01$), Cognitive Function ($r=0.28$, $p<0.05$), Health Distress ($r=0.52$, $p<0.01$), Overal Qol ($r=0.49$, $p<0.01$), Sexual function ($r=0.33$, $p<0.05$), Change in Health ($r=-0.17$, $p<0.05$), and Satisfaction with sexual function ($r=0.33$, $p<0.05$).

Conclusions: There is a statistically significant correlation between the variables, suggesting that Hope can play an important role in the Quality of Life of patients with multiple sclerosis especial in domains as perception of Well-being, Health in General and Social Function and Distress.

Keywords: Hope; Quality of Life; MSQoL-54; Multiple Sclerosis

Introduction

Multiple Sclerosis (MS) is an auto-immune mediated neurodegenerative disease, with unknown cause, that strikes people already in early adult age and it affects approximately 1 million adults in the World [1-4], MS is multifactorial and is outstanding in its wide range of symptoms and unpredictable disease course, including a benign course, a relapsing-remitting course (exacerbations and remissions),which invariably turns into a secondary progressive course, and a type that is progressive from its onset. There have been several advances in recent years [2,5].

People who have long-term disabling conditions are frequently confronted with psychological and physical challenges that vary not only from year to year but also from day to day. MS is highly unpredictable in terms of symptoms, disease course and the resulting degree of disability. Each person with MS encounters different problems accompanied by a range of unique experiences and emotions. Inevitably this affects individual perceptions concerning needs and preferences for health and social care [6,7].

The concept of Quality of Life (QOL) has received much attention as traditionally used measures of medical outcome such as morbidity and mortality do not sufficiency capture the full impact of medical interventions. This is especially the case for MS. It is necessary to understand the multidimensional impact of chronic diseases such as MS through consideration of physical and social functioning and emotional well-being [8-12]. In MS, physical symptoms or neurological impairment were traditionally the main characteristics used to analyze the severity of the disease. In recent years, QOL has been used along with scales that measure the severity of MS (for example, the Expanded Disability Status Scale [EDSS] developed by Kurtzke in 1983 [13] as a partner for measuring the subjective and functional effects of the neurological impairments, the disability, and handicap aspects [2,6,7,14].

Accordingly, with Pais-Ribeiro [15] QOL is an everyday language concept with a relatively short history in the health field. It became a principal endpoint in health care as a consequence of the development of patients' rights movements, and it is important for clinical, economic and political decisions.

A more specific term for QOL is Health Related Quality of Life (HRQoL), which is disease-oriented, relating to symptoms and impairments from patients' perspectives [16,17]. Vickrey and collaborators [17] defines HRQoL as a multi-dimensional construct that includes physical, mental and social health. To measure the construct in people with MS, this group developed the self-report Multiple Sclerosis Quality of Life - 54 (MSQOL-54). In recent years, there has been an expansion of studies examining factors associated with HRQOL in MS [18-22].

Collectively, these studies have revealed correlations between several clinical variables and HRQOL indicators. In either correlation

or regression analyses, poor HRQOL was predicted by progressive disease course, physical disability, self-reported, fatigue, depression, and cognitive Impairment.

Clinicians must understand the moderating factors of these trajectories. However, many individuals with MS adapt well to modest disabilities and some individuals cope well even when faced by severe physical setbacks. Positive personality factors are important in HRQOL, and remain almost completely unexplored in MS. Similarly, coping styles are notable moderating variables for patient and carers, reinforcing that psychological and personality variable are becoming part of mainstream practice [9,23,24].

A focus in health psychology is on promoting and maintaining good health and preventing, detecting, and treating illness: Hope may be implicated in each of these areas [25,26]. These authors examined Hope in the context of two types of prevention, primary prevention, which entails those cognitions or actions that are aimed at eliminating or reducing subsequent physical limitations [27,28], and secondary prevention, which reflects those cognitions or actions that are aimed at eliminating, reducing, or containing problems once they have already appeared [26,29].

After the development of an illness, the role of Hope would emerge in the context of secondary prevention-perhaps helping people to cope with pain, disabilities, and so forth. Research have found that higher Hope is related to better adjustment in coping with major burn injuries and spinal cord injuries [30], fibromyalgia [31], blindness [32] and women with cancer [33]. Kylmä [34] show important relationships between Hope and QOL in individuals with HIV. Hope variable have been studied in MS [35].

Snyder and collaborators [36] offered the following Hope definition is a positive motivational state that is based on an interactively derived sense of successful (a) agency (goal-directed energy), and (b) pathways (planning to meet goals): the trilogy -goal, pathways, and agency - are core concepts in this definition. The goal is the cognitive component that anchors Hope theory [37,38].

Beste [39] differentiates, between Hope for a cure or remission, and Hope that focuses on meaning in life. Hope allows for a multifaceted construal that allows patients to autonomously determine what is meaningful to them. Others have asserted the value of Hope to patients that exceeds the compliance determined by medical professionals, one that endures beyond the biological decline associated with terminal illness.

For Elliott and Olver [23] and Bryant and Cvengros [40] it can be seen as a social practice, delineating how Hope (and hoping) plays out in interpersonal and everyday interaction, suggesting practical guidance to those wishing to value Hope, particularly with regard to patient well-being. The healthcare professionals can more usefully consider the function and consequences of Hope, viewing it as an attempt to articulate, share the value with others, and those things that connect the patient to what gives meaning to their lives, and ultimately to life.

The objective of this study is to describe the relationship between Hope and HRQOL in patients with MS.

Materials and Methods

Design

The study was descriptive, correlational and exploratory.

Participants

Those eligible for the study were a consecutive sample of outpatients with a diagnostic of MS, aged 18-65 years who were treated and followed at the neurology department of Central Hospital of Lisbon – Portugal. Disability was defined by the EDSS [13] or cognitive impairment (defined according to the EDSS criteria of Mental Status Examination). 280 MS patients with a definitive diagnosis for more than one year participated in the study, after accomplishment of the procedures defined by Helsinki Declaration, the hospital rules and the Portuguese law. Patients were accessed via their physician at the neurology department. They were eligible for inclusion in the study if they met the following criteria: diagnosis according to relevant medical criteria, between 18 and 65 years, being diagnosed at least 1 year ago, EDSS score under 7. The mean age of participants was 40 years, 71.3% were women, 61.1% were currently married, 63% active workers, mean school level of 12 years, and scores of EDSS with a mean of 2.8.

Materials

The Multiple Sclerosis Quality of Life-54 (MSQOL-54 is a multidimensional health-related quality of life measure that combines both generic and MS-specific items into a single instrument [17]. It is a questionnaire containing 54 items, thirty-six of the items were taken from the RAND 36-item Short Form Health Survey (SF-36) [41], with additional 18 items specific for MS. Taken together, the 54 items make up MSQoL-54 survey developed by Vickrey and collaborators [17]. The disease-specific MSQoL-54 was developed based on the generic SF-36 Medical Outcomes Instrument Study and consists of 12 subscales, eight of them from the 36-item SF-36. The subscales are physical function, role limitations-physical, role limitations-emotional, pain, emotional well-being, energy, health perceptions, social function, cognitive function, health distress, overall quality of life, and sexual function. The summary scores are the physical health composite summary and the mental health composite summary: here are also two additional single-item measures, to tap satisfaction with sexual function and change in health.

This scale can be used as a self-report, as interview, or as postal questionnaire. Each subscale is scored from 0 to 100, with higher scores indicating better QOL. Subscale scores can be weighted and summed to generate physical and mental health composite scores [17]. Psychometric Proprieties of the 12 MSQOL-54 subscales show good internal consistency with Cronbach's alphas ranging from 0.75 to 0.96. Test-retest reliability for these 12 subscales is also good with interclass correlation coefficients ranging from 0.66 to 0.96. There is evidence for the validity of the MSQOL-54. Vickrey and collaborators [17] report in one study, that the physical function and role limitations-physical subscales were the ones that best discriminated between MS patients and the normative U.S. population. In the present study (Table 1) we found good internal consistency with Cronbach's alphas similar to the original version, ranging from 0.76 to 0.96.

Test-retest, was performed in the original study one month after the first application and, in our study, two months later. As in the

Table 1: Descriptive statistics and Alpha reliability for the MSQOL-54 (in brackets the values of the original study of Vickrey and collaborators [17].

Scale	Number of items	Mean	SD	Cronbach' alpha
Physical Health	10	58.7	29.2	0.93 (0.96)
Physical Role Limitations	4	58.6	31.1	0.93 (0.86)
Emotional Role Limitations	3	49.8	37.8	0.96 (0.84)
Pain	3	66	25	0.88 (0.92)
Emotional Well-Being	5	50	25.7	0.86 (0.87)
Energy	5	47	22.2	0.81 (0.84)
Health Perceptions	5	46.3	18.7	0.76 (0.80)
Social Function	3	67.9	23.8	0.68 (0.75)
Cognitive Functioning	4	69.1	25.2	0.89 (0.90)
Health Distress	4	55.8	26.1	0.85 (0.91)
Overall QOL	2	61.2	18.7	0.68 (0.86)
Sexual Function	4	27.7	31.6	0.89 (0.85)
Change in Health	1	49.5	23.9	
Sexual Satisfaction	1	38.4	27.4	

Notes: MSQoL-54: Multiple Sclerosis Quality of Life - 54.

Table 2: Descriptive statistics and Test- Retest for the MSQOL-54.

Scale	Number of items	Test-retest Alpha
Physical Health	10	0.85 (0.96)
Physical Role Limitations	4	0.82 (0.67)
Emotional Role Limitations	3	0.71 (0.73)
Pain	3	0.83 (0.86)
Emotional Well-Being	5	0.74 (0.85)
Energy	5	0.86 (0.85)
Health Perceptions	5	0.87 (0.69)
Social Function	3	0.81 (0.77)
Cognitive Functioning	4	0.86 (0.86)
Health Distress	4	0.71 (0.78)
Overall QOL	2	0.60 (0.87)
Sexual Function	4	0.85 (0.94)
Change in Health	1	0.87 (0.86)
Sexual Satisfaction	1	0.31 (0.90)

Notes: MSQoL-54: Multiple Sclerosis Quality of Life - 54 [17]. Between the brackets are the values of the original.

original scale results show good correlation values (Table 2). Only in the dimension, sexual satisfaction, it was not found good value of test-retest reliability in our population. Test-retest reliability for the 12 subscales, and the two items range from 0.60 to 0.96.

Hope Scale [37] consists of 12 items, four agency, four pathways, and four distracter items. In completing the items, respondents are asked to imagine themselves across time and situational contexts. The questionnaire shows good internal consistency in different studies (alphas ranging from 0.74-0.88 for the overall scale, of 0.70-0.84 for the agency and 0.63-0.86 for pathways subscales separately), and temporal reliability (tests-retests ranging from 0.85 for 3 weeks to 0.82 for 10 weeks. Moreover, the scale has received extensive concurrent and discriminant validation support, as well as experimental

Table 3: Descriptive statistics and Alpha reliability for Hope Scale (in brackets are the values of the original study).

Scale	Number of items	Mean	SD	Cronbach' alpha	Test-retest
Agency	4	22.3	5.9	0.84 (0.71)	0.77
Pathways	4	23.3	5.1	0.89 (0.67)	0.66
Total	8	45.6	10.1	0.81 (0.75)	0.77

Notes: HOPE: Hope Scale.

Table 4: Correlations between Hope Scale and the domains and items of MSQOL-54.

Domains of MSQoL-54	HOPE		
	Pathways	Agency	Total Scale
Physical Health	0.19*	0.24*	0.24*
Physical Role Limitations	0.19*	0.25*	0.25*
Emotional Role Limitations	0.30*	0.35*	0.35*
Pain	0.20*	0.31*	0.28*
Emotional Well-Being	0.42**	0.47**	0.48**
Energy	0.37*	0.39*	0.42**
Health Perceptions	0.36*	0.39*	0.41**
Social Function	0.40**	0.42**	0.45**
Cognitive Functioning	0.22*	0.29*	0.28*
Health Distress	0.45**	0.50**	0.52**
Overall QOL	0.41**	0.48**	0.49**
Sexual Function	-0.32*	-0.29*	-0.33*
Change in Health	-0.13*	-0.17	-0,17*
Sexual Satisfaction	-0.28*	-0.34*	-0.34*

Notes: MSQOL-54: Multiple Sclerosis Quality of Life - 54; HOPE: Hope Scale. *p <0.05; **p <0.01, p <0.001

manipulation-based convergent validation [36,42]. The scale has been used with MS patients [20,33], patients with spinal cord injuries [30], blind older adults [32], graduate students [43], and psychiatric outpatients [44]. Descriptive statistics and reliability with our sample are provided in Table 3. Higher scores indicate a higher level of Hope. Also included in the table are the Alpha reliabilities for the scales as well as, where applicable, those obtained by Snyder et al. [36].

It can be seen in Table 3 that the reliabilities obtained in our study are generally comparable to those obtained by Snyder et al. [36] and range from 0.81 to 0.89.

Statistical analysis

Data where analyzed using the statistical program Statistical Package for Social Science version 23, the data on the demographic questionnaire were treated descriptively in view of the frequency distribution of the variables. We used Pearson correlation test to assess the relationship between variables and the various dimensions of the scales. The correlation is a measure of linear association between quantitative variables [45].

Results

The correlations between Hope scale and the domains or suscales of MSQOL-54 are shown in Table 4.

The analysis of Table 4 shows that there is low to moderate statistically significant correlations between the dimensions of

MSQOL-54 and dimensions Agency, Pathways and total score of Hope Scale. Correlations tend to be higher for the Agency dimension than for the Pathways dimension. For Agency, correlations are higher for dimensions, Emotional Well-being, Energy, Health Perception, Social Function, Health Distress, and Overall QOL. For Pathways, correlations are higher for dimensions Emotional Well-being, Social Function, Health Distress and Overall QOL.

For the total Hope scale score, we tend to find moderate values for the correlations with MSQOL-54. Results are higher for dimensions, Emotional well-being, Energy, Health Perception, Social Function, Health Distress and Overall QOL, with emphasis on the dimensions Emotional Well-being, Social Function, Health Distress, and Overall QOL. Results show that the QOL dimensions more related with Hope, are emotional well-being and distress.

Discussion

The result of our study suggests that Hope and QOL as measured by MSQOL-54, are statistically significantly correlated. The QOL is a very important concept for the health field outcomes, due to its multifactorial scope [15,17]. The results show that Hope can be an important factor for patients with MS as well as other chronic disease, as shown by studies [30-32]. Hope was statistically significantly correlations with all domains of the MSQOL-54. This finding is corroborated by similar findings, in which Hope was found to be an important internal resource for the increased functioning of patients [22,34,39].

Correlations are higher for the dimensions, emotional well-being, vitality, general health, social function, health distress to health and quality of life in general. We can conclude that the greater the perception of Hope, the greater the perception of QOL in people with Multiple Sclerosis. Dimensions related to the physical component of MSQOL-54 are not greatly related with Hope, except Energy. The dimensions of Emotional Well-Being, General Health, Health Distress, and Quality of Life in General are related with Hope. In this construct also seems that Energy and Social Function show high correlations with Hope. Hope seems to have an important role in Social Function since the values of correlation between the Hope dimensions (Agency, Pathways) and Social Function are moderate. The literature reported by Ebright et al. [33] and Snyder et al. [38] that highlight the role of Hope in the adaptation of coping styles in the face of disease, and, in particular, when there exists incapacity, suggesting that Hope diminishes the stressful factors related to health, through the implementation of goals they seek. Then, Psychological intervention programs promoting Hope seems to be useful to promote QOL in people with MS.

Research results suggest that high hope is associated with high QOL in individuals with MS, especially when there is disability, and for the mental health component of QOL.

Declaration

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